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ABSTRACT

This paper explores the differential development of Connecticut's voluntary Acquired Immune Deficiency Syndrome (AIDS) projects as they move from grass-roots organizations that are akin to social movements to street-level bureaucracies and finally to managed professionalized agencies. The federal government has identified an appropriate continuum of care for which it will take a narrowly defined responsibility. The literature describes a shift from an institutionalized approach to care to a greater emphasis on self-help, stimulating a need for grass-roots organizations to meet this demand. The AIDS epidemic illustrates how services have become the responsibility of families and an emerging social network of volunteers. Connecticut's AIDS projects are representative of this continuum of grass-roots community organizations that move to street-level bureaucracies and into professionalized agencies. The biggest and oldest project is AIDS Project New Haven that was organized as a grass-roots organization. There has been a tendency to formalize activities in these organizations. If AIDS projects remain flexible and innovative and are not forced to compete with one another for funding, they have an important role to play in providing service and advocating political change. (SM)

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FROM SOCIAL MOVEMENT TO SOCIAL ORGANIZATION: VOLUNTARY AIDS PROJECTS IN CONNECTICUT

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FROM SOCIAL MOVEMENT TO SOCIAL ORGANIZATION:

VOLUNTARY AIDS PROJECTS IN CONNECTICUT

by George A. Appleby and Barbara G. Sosnowitz

The federal government has identified an appropriate "continuum of care" for which it will take a narrowly defined responsibility. The growing literature describing the privatization of welfare will support the observed shift from an institutionalized approach to care, to a greater emphasis on self-help. This represents a shift of responsibility for the ill back to the family. The AIDS epidemic is illustrative where services have become the responsibility of families, lovers, friends and an emerging social network of volunteers. The community being assigned the task of both providing the service to remedy the problem and means for protecting itself from the problem.

The authors will explore the differential development of Connecticut's voluntary AIDS projects as they move from grass-roots organizations, akin to social movements, to street-level bureaucracies, to managed professionalized agencies. They will discuss how voluntary AIDS projects have the potential to become a political base for PWA's to criticize and demand effective service. The authors also point out the potential risks for professional cover-up, as well as AIDS projects becoming a means for "passing-the-buck" to families. The emphasis on self-help groups dealing with personal problems redirects the attention away from the inherently political nature of the AIDS epidemic.

Since 1981, a basic understanding of the clinical features and epidemiology of AIDS has developed. Compared to many diseases, knowledge about AIDS has accumulated at an amazingly fast rate. Despite the rapid progress, though, there remains substantial gaps in our understanding of this disease, and, to date, there is no cure or preventive vaccine.

As of May 1987, over 35,000 AIDS cases had been reported in the U.S., over one half have died from this fatal disease. Connecticut reported over 400 cases or 14th among the states. Seven of Connecticut's cities are among the top 50 in cases per capita: New Haven, Hartford, Norwalk, Stamford, Bridgeport, Danbury and Waterbury.

This paper will focus on the political nature of AIDS in its conceptualization or social construction and its governmental and community response. This context has been a major influence on the specific type and mix of public and voluntary services available in each community. Hasenfeld and English (1983) argue the uniqueness of the human service organization and note the significance of its economic-political environment in relation to its structure and development. These are limited and influenced by (a) the cultural and normative framework within which it functions; (b) it legitimation in the community; (c) the attainment of necessary resources (e.g., technology, personnel, funds); (d) input to be worked upon (e.g., clients; and (e) the disposition of its products (e.g., services). This formulation

will guide much of our discussion.

CULTURAL FRAMEWORK:

The federal government has identified an appropriate continuum of care for which it will take a narrowly defined responsibility. The privatization of health and welfare, a social policy aggressively promulgated by the Reagan administration, can be seen in the shift from an institutional approach to care to greater emphasis on self-help. The community and the family have been given greater responsibility for its members. Specifically in the AIDS epidemic, services have become the auspices of families, lovers, friends and an emerging social network of volunteers. These being assigned the task of both providing the service to remedy the illness and the means for protecting itself from the problem.

The moral construct of the causality of AIDS fits with recent campaigns in the United States to encourage individuals to be responsible for their own health. And, "It is more than coincidental that the at-risk life styles, which we are all admonished to avoid, are frequently the type of behaviors which depart from and, in a sense, jeopardize the prevailing puritanical, middle class ethic of what ought to be" (Mckinlay, 1974, p. 15). The person with AIDS has either done something he or she was not supposed to do or has failed to take proper precautions.

Connecticut's AIDS projects are representative of this

continuum of grass-roots community organizations, akin to other early social movements, moving from street-level bureaucracies to professionalized agencies sanctioned by larger human service organizations. This progression will be included to illustrate the political and organizational nature of this illness.

The way in which illness is handled inevitably reflects the dominant ideology of the society. In the U.S. the concurrence of a weak public health sector and a strong emphasis on community identity has helped shape the particular form of the AIDS epidemic. Through its short and virulent history, AIDS has been seen as a gay disease by nongay people, as a disease of outcasts by those in the mainstream, as a problem of cities by the federal government, and as a problem of the United States by the world Community.

Altman (1987) suggests that we are not used to thinking of illness as political. Yet, so much of health is due to social and political factors. Every culture has an ideological system that explains illness, and within the explanation is often embedded the type of treatment that is sanctioned for its cure (Kleinman, 1980). The boundaries between medical and social factors are blurred: the inconsistency of care in hospitals and from the medical profession, the moral environment in which education is conducted for the public, are all affected by political and cultural factors. The half-hearted response of governments, and the considerable stigmatization of those struck

by AIDS help to give this epidemic its characteristics. Even when we recognize the political dimension to health care and research, it is still difficult to conceive of disease itself as a political construct. We see the determinants of health and illness as predominantly biological, and assume that medicine as a science is capable of producing an unchallengeable and autonomous body of knowledge not tainted by wider social and economic considerations (Doyal, 1979).

What is clear is that the way in which AIDS has been perceived, conceptualized, imagined, researched and financed make this one of the most political of diseases. Altman (1987) identified a number of circumstances that set AIDS apart from other epidemic and help explain why it has been so politicized. First, it has occurred at a time when modern medicine was believed to be well on the way to abolishing epidemic diseases altogether. The onset of AIDS unleashed disputes over the mobilization of resources for research and care, as well as over scientific theories and crushed the belief that modern medicine can control and cure any disease that comes along.

Second, AIDS as it has presented itself in the western world, has been very specific in the groups it has affected, primarily male homosexuals who already occupy stigmatized positions within society. The epidemiology and the social response to the disease are intertwined with major changes in the social construct of homosexuality as it has emerged in the West

(Levine, 1987). Homosexuals surfaced as a recognized social, cultural and political minority during the 1970s. The AIDS epidemic came along just when the old religious, moral and cultural arguments against homosexuality seemed to be collapsing. This increasingly visable minority served as a basis for an organized response to AIDS. AIDS political and welfare organizations were formed early in the epidemic. As the spread of AIDS became linked in the public imagination to the very presence of homosexuals, the gay visibility and affirmation of the past decade generated some very nasty scapegoating.

Third, AIDS was firmly linked with sex, although this is not the only way it can be transmitted. Brandt (1985) while commenting on venereal disease appears to reflect the general public attitude toward AIDS that a sexually transmitted disease is a revenge against the sexual revolution and modern medical technology that helped to make it possible.

Fourth, AIDS seemed at first to be a disease primarily confined to gay males. This has shaped the entire discourse surrounding the disease. Other groups at risk are often too invisible to merit attention forcing AIDS to be seen as a gay rather than a health issue. It makes sense that the more a disease is experienced collectively, particularly by an already stigmatized group, the clearer will be its political dimensions.

In every other major Western country there exists some sort of national health insurance, so that people struck with

catastrophic illness do not find themselves scrambling to pay for basic care. In most other affluent societies, basic welfare services required by the seriously ill are provided by the State. Both the social construction of and the governmental response to AIDS in the U.S. have been clearly affected by the dominance of Reaganism in the eighties. One of the central questions raised by this disease is the ability of the State to care for what is commonly viewed as the first requirement of government, namely the protection of life itself. The Reagan administration has constantly called for services to be provided by the community. The proported community based programs backed by state and federal governments were to be in place in the 60's. In reality, these community services never materialized or have been a scrambled mess receiving little state and federal support.

COMMUNITY LECITIMATION:

The idea of community has powerful political and psychological implication, and has undoubtedly been strengthened by the AIDS crisis. It is this sense of being ignored by the larger society that has motivated thousands of gay men, and lesser but important numbers of lesbians, to develop communal organization, hot lines and fund-raising events to meet the challenges of AIDS. For the person with AIDS, the social context of care is a hostile one. The medical environment generally antagonistic to all patients is particularly so to those with a terminal disease. Add to this the fear of contagion and homophobia, we can begin to

understand a willingness to keep a persons with AIDS isolated. The ideology of individual or family responsibility for care lends itself to medical obfuscation. AIDS organizations fulfill a number of needs. They offer practical help to those with AIDS and their families, friends and loved ones to bridge the enormous gaps in the health and welfare systems. They provide information for both the general public and risk groups and increasingly have focused on prevention education. And the struggle for elementary government recognition, support and civil rights.

Although the activities of AIDS projects tapped new energies and leadership, they also built upon existing organizations and appealed to the existing rhetoric of gay community and solidarity. To be actively engaged in caring for people with AIDS can be cathartic; work is a solace from anxiety and to make common cause with one's own a unique comfort. As Kayal (1987, p. 21) an AIDS project member put it: "Aids allowed a commonality like gayness to become the basis for community. And for us, it is life in community, the kind of communal environment that Gay Men's Health Crisis created, which leads to political activity."

People fill emotional and political needs in many different types of secondary groups or organizations. Appleby (1985) describes a rich organizational research literature illustrative of the range of options groups might choose to meet their needs. A discussion, more descriptive than analytical, of several key concepts will serve as a framework for understanding the

differential development of AIDS projects in Connecticut.

The best known organization to come out of this epidemic is New York's Gay Men's Health Crisis (GMHC), founded in 1981 by a group of men, most of whom already had friends or lovers with the disease. The early focus of GMHC was on education and fund-raising for research. By mid-1984 GMHC had become institutionalized with an impressive center and an expanding range of activities and a rapidly growing professional and volunteer staff. Inevitably, such a large and rich organization has had to adopt a bureaucratic structure. The administrative structure became necessary partly due to its success in fund raising and grant writing. Dealing with so much money and government agencies requires a certain professional expertise.

As the crisis expanded, there has been a growth of volunteer organizations. In addition, as they began to offer service, there was a growing recognition that only a combination of communal and government efforts could provide the very complex welfare and educational services that AIDS demands.

The AIDS projects in Connecticut reflects a mixture of big city sophistication and small town floundering. The biggest and oldest project is AIDS Project New Haven which was established in 1983 and modeled after GMHC. AIDS Project Hartford opened in 1985. Since 1986 projects have started in both big cities like Bridgeport, New London, Stamford and Waterbury, and much smaller ones such as Greenwich, Litchfield, New Britain and Norwalk.

Groups like GMHC and the AIDS projects in Connecticut seem to represent a development among gay men similar to that which took place earlier among feminists. Fagan, Friedman, and Wexler (1984) and Star (1983) note the role of medicine and psychiatry in early feminist formulations of women's health care needs and latter developing services for battered women. Male dominated medicine was targeted often as a source of the problem while self-help not professional services were deemed the most effective response from a community of concerned women. Similar responses appeared in the first phases of the AIDS epidemic, specifically in the politically active gay community. However, because of the demand for an immediate practical response and the need of special medical expertise medicine and health as social and political issues are seldom raised by AIDS projects today.

The preceding discussion offers an explanation of the differential development of Connecticut's voluntary AIDS projects. The New Haven project was founded by a small group of concerned people, most of whom were gay, some of whom had recently experienced the death of a close friend or lover from AIDS. At about the same time, the Yale University School of Medicine was collecting the names of 1,000 gay men who would be willing to participate in a research project the school was hoping to conduct. Concurrently, Yale New Haven Hospital initiated its AIDS Care program. The planning meetings provided a natural forum for discussing a response to the horror of what

was happening. Thus AIDS Project New Haven (APNH) was formed with a core of a dozen men and women, half of whom were health professionals. APNH's structure assumed characteristics most commonly identified with grass-roots organization, akin to liberationist or social movements (Litwak, 1970; Perlman, 1979). While individuals attempted to remedy social purposes through a loosely structured format initially, there has been tendency to formalize activities which appear to address the organization's goals (Katan, 1984). Individuals within APNH pressed for greater role clarity as members who had greater power and status tried to define not only their role but those of others. In the anticipated process of specialization of functions and roles, there emerged an inter group or interprofessional conflict.

SERVICES:

Hasenfeld (1983) and Vinter (1963) in their discussion of human service organizations differentiated between people processing, people changing and people sustaining organization. Each type of organization has a constellation of goals in relation to its consumers, clients, or patients. Schecter (1982) has applied these concepts to direct service activities which appear most relevant to aids projects. The purpose of people processing is to assign a label or public status to clients, which then makes them eligible for certain services or responses from others. Scher (1987) reports that the functions of data collection, assessment and eligibility determination become

central in this type of organization. People sustaining activities involve attempting to prevent, maintain or retard deterioration. The medical system assumes these activities for AIDS patients, in direct contrast to the cure focus typical of health care. This curing or treatment focus called people changing, valued by professionals more than the other activities is more closely associated with health and human services. Thus the organizational press toward counseling and psychotherapy becomes a marker in most human service agencies, AIDS projects have not been exceptions.

As programs develop preference for one form of functioning over the other, reflect the dominant ideology of the more powerful members. The auspices of each project is of note. The earliest activities of APNH reflected this inherent conflict, just as the current preoccupation with reorganization has elements of this struggle.

The development of AIDS Project Hartford (APH) parallels the strains experienced by APNH in moving from an non-instrumental, consensus decision making structure, to a street level bureaucracy with greater identification with a specific volunteer group. It developed different internal structures to accommodate conflict. Unlike New Haven, clergy most of whom were gay, were the primary professional group associated with its founding. The organizational ideology and experiences of these men and women, their valued place in society

and their professional relationships with one another, and the community stands in contrast to APNH. Their resistance to bureaucratic structure appears to be widely supported by its lay membership. Never-the-less, APH finds itself becoming increasingly more structured as it tries to conform with the expectations of local human service agencies and state funding requirements. Bridgeport was initiated by a consortium of health and social agencies with little history of interorganizational cooperation. Greenwich and Norwalk have been developed by public health personnel with well defined agency connections. Stamford owes its earliest development to the Red Cross.

RESOURCES:

Unlike Hartford or New Haven, these newer AIDS projects do not build upon a well developed gay and lesbian community. These organizations seems to have difficulty establishing a critical core of volunteers, launching fund-raising strategies, and defining a service domain. Four of the smaller organizations have decided to merge into one regional project with full-time staff coordinating the efforts of each town. This reginal cooperation represents far greater and more rapid growth than is characteristic of APNH or APH. It will be of interest to discern whether this particular project's growth backed by state and federal funding is the result of their nongay sponsorship, greater skill on the part of their organizers, or a clearer definition of function acceptable to the larger societal service

organizations. The other AIDS projects are relatively new but share the experiences of any developing human service organization. Differences have arisen as to which issues to give priority, and questions regarding the style or timing of program development seem to be emerging, however, they are so new generalizations would be premature at this point.

Up to this point, funds for the larger projects have been raised by the gay and lesbian community primarily. This may drastically change with greater involvement of state and federal agencies as contractors of health and welfare services for persons with AIDS. It is this anticipated change that may have the greatest impact on the future organizational structure of all of community based projects. Observations of the Women's Movement demonstrate the trend most likely to take place. Battered women's shelter programs have shifted from loosely structured services offered by battered women themselves to better financed of professionally managed programs. State funded programs require a routinization and consistency programs run by health and human service professionals. Of concern is the success of grass-roots programs and where it could lead. The loss of autonomy and flexibility could eventually mean its demise or incorporation into the bureaucracy of human service.

CLIENTS:

It is also conceivable that as AIDS projects expand services to others with AIDS the emerging political orientation for gay

causes will be depleted (Sosnowitz, 1987). Many members of Aids projects joined to gain support against negative social and psychological consequences of being gay. The ideology of at-risk behavior and personal responsibility influenced projects to educate its members as well as the community at large with startling results. These projects, formed by grassroot, young politically savy, middle class homosexuals to retain some control over their lives were potential political dynamite. The projects originated in response to the lack of professional social services available to gay men with AIDS. And had they not taken over the tasks of providing care, themselves, there is question as to how the first cohort of men would have been treated by the society at large. These projects were on their way to be coming a very volatile source of change. However, the need to fill the gap of health care has overloaded them. AIDS projects have administered services not only to homosexuals with AIDS but in addition, drug addicts and prostitutes. The projects have become so stretched they have little energy, money or man/woman power left to demand political amd medical changes. By providing the very needed immediate care services to the victims of AIDS, they have lent themselves to victim-blaming by masking the social response to the disease and those affected. As the necessary federal and state monies begin to materialize, and the bureaucratic regulations emerge, it is feared that many of the AIDS projects will lose the very fiber of political community on

which they were built.

SUMMARY:

It is possible that some of these projects will not progress any further because of: (a) an inability to develop stable bases of support in the community, particularly in cities without an organized gay and lesbian presence; (b) failure to establish crucial and systematic linkage with other human service agencies, particularly with projects unable to attract volunteers with knowledge or skill valued by these organizations; (c) a lack of formalized methods to publicize services, particularly in those organizations that resist any trapping of formality; and (d) difficulties in developing effective staff-client relations, particularly where volunteers and clients are from different social and ethnic groups as well sexual orientations.

Each of the above scenarios will result from an economic-political environment that is changing in parallel fashion with the evolution of community based AIDS projects. Some type of change is inevitable and appropriate. So far we have seen the impact of the social construction of this epidemic, the demands of the economic-political environment, and the requirements of human service organizations upon the AIDS epidemic. The number of persons with AIDS doubles each year. All the needs of persons with AIDS and those caring for them have not been met by mainline organizations providing health and social services. If AIDS projects are willing to remain

flexible, innovative and not forced to compete with one another for funding, they have an important role to play in providing service and advocating for political change. Perhaps survival for individual projects depends on narrowing service to one particular target group, working side by side with other projects offering service to a different vulnerable population. Another option could be to develop complex administrative structures to accommodate separate and diverse services staffed by a broad range of volunteers. Only time will tell.

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